Ambition and Ambivilence

AMBITION AND AMBIVALENCE: ENGAGEMENT AND POLICY DIALOGUES IN ARGENTINA

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Drawing on empirical research conducted in Argentina through the ESRC-funded 'GET: Social Values Project' (see http://www.law.ed.ac.uk/ahrc/esrcvaluesproject/), this Policy Brief (1) places stem cell and regenerative research in the broader bioscience and health research context, (2) provides evidence of Argentine stakeholder views on the state and value of public engagement in this field, and their desires with respect to science democracy, and (3) offers insights into how this evidence is relevant to bioscience and health research policy options in Argentina.

BIOSCIENCES IN CONTEXT

In the evolving knowledge-society and bio-economy, capacity, activity and innovation in high technologies are widely seen to be (and therefore are) important elements of sustainable development, critical to social and economic life, which is increasingly characterised by unstable global economics, collaborative international science, near instant communication, and, arguably, socio-cultural convergence. Both governments and non-governmental organisations are seeking to use the biosciences (regenerative medicine, bio-nanotechnologies, etc.) as an engine for growth and competitiveness. Regenerative medicine in particular, and its related biotechnologies (which include stem cell research) have emerged as particularly powerful mobilisers. Respondent 5 (R5) in the GET: Social Values Project stated:

> … As a consequence of the interest of the Minister of Science, I think this [stem cell research] is one of the things that is growing fast in the country. … Now we have, besides these ten [stem cell] projects, this cluster for stem cell research that involves nine different institutions in the country with fourteen different projects.

"It's a very interesting line of research, quickly growing here, quickly growing."

R7 concurred that stem cell science is becoming important, and R21 was hopeful that concrete developments could be made in Argentina in the upcoming years such that new models and new techniques for applying stem cells could be achieved which might facilitate clinical practice.

However, regenerative medicine and its related biotechnologies are sometimes controversial because they are 'change-instigators'. For example, they: redefine how we characterise health and ill-health, normalcy and abnormality; influence how we investigate health and disease; transform our ideas of what might be possible from a health perspective; and shape how we structure healthcare delivery. Of course, given this, the choice of what research gets funded is also very important, and says a lot about scientific possibilities and how certain (governmental) stakeholders wishes to see science and society progress. In any event, the combination of the (sometimes) controversial nature and of their perceived power and potential of these sciences, makes governing activities in this

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field very important, and most respondents in the GET: Social Values Project felt that government regulation in this field is important, if politically difficult and potentially restrictive of science possibilities.

PUBLIC DEBATES AND SCIENCE LITERACY

Most respondents in the GET: Social Values Project had very little knowledge of any public debates on stem cell research or regenerative medicine beyond their own activities, which were mostly restricted to professional circles. The identified a number of barriers to public debate, including the following:

1. the powerful and entrenched (so-called) anti-science position of the Catholic Church which does not foster rational debate;[1]

2. the largely conservative media which is more interested in spectacular headlines and selling copy than in educating or expressing nuance;

3. the legislative branch of government, which is reliant on the former two institutions and which is highly scientifically illiterate; and

4. the social context of Argentina which is not one of easy open debate and which is faced with a variety of social problems more pressing than social engagement around science.

These barriers represent challenges to development of good science communication practices in Argentina, and therefore hurdles to the improvement of science literacy in Argentina. Respondents felt that public understanding of stem cell and related research practices and their (realistic) objectives was very low, and that there existed a lot of fantasies and bad information which hindered people from having rational discussions.

Importantly, respondents did not equate low science literacy rates with resistance to science; rather they felt that people were very positive about science and research, but did not understand it well and therefore could not discuss it effectively or support it openly. Thus, despite the above barriers, there was a strong desire amongst respondents to interact with society on bioscience issues. R11 stated:

> I want social debate about stem cells, but I think this is not currently an agenda of the government to have this kind of debate. … We in society need to think, and to express opinions regarding stem cell therapies.

Generally, respondents were unequivocal that not enough is said about science – and in this case stem cell research – in Argentina.

DESIRES FOR ENGAGEMENT AND SCIENCE DEMOCRACY

It was generally recognised that not much is said about stem cell research and regenerative medicine in Argentina. Debate is taking place at elite science levels,

"Informing people [is important], but I mean really informing people. I'm not talking about propaganda, I'm talking about them saying - 'This is what [stem cell research] is, these are the costs and these are the costs, there are many things we don't know' - because I think that kind of view is good from the scientific community."

"[People] have this simple view of [stem cell research]. They think we are very close. They think that this will prevent future diseases [and] cure all genetic diseases. I mean, there is a lot of bad information and fantasy. And people get very disappointed when someone says, 'Look, we are far away from having this as a normal therapy.'"

[1] It is important to note that, while the Church emerged as a source of (often deep) concern and scepticism for many of the respondents, no Church officials were interviewed in the course of this research, a lacunae we hope to fill in future research projects. As such, we make no claims as to the actual simplicity or complexity of Church positions.

in science and ethics groups, but not in public, and there is a reluctance to discuss stem cell research (and indeed reproductive and regenerative medicine) in formal environments, in part because of the anticipated reaction of the Church, which was viewed by a number of respondents as highly antagonistic to stem cell research and to scientific knowledge-creation more generally.[2]

Respondents saw a need to be expanded the scope of, as well as the possibilities for, debate; public discussion should include issues about the status of the science, research planning, bioscience boundaries, and desired therapies, and should dispel fantasies and fallacies. The value of real debate was noted by multiple respondents. R3 stated:

> I think it [debate] is beneficial. … You have to discuss things. You have to make a debate [with different] points of view. … There are ethical terms which we need to discuss. … How you relax that boundary, how you push that [one]. So that should be a discussion between the scientists and society.

R5 stated:

> [E]ach country should try to contribute to the debate … . I don't know the view of my country. I could guess, but I don't know. … I would like to know what my country's people would like to say about [stem cell research and bioscience more generally].
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> [It] is very important to open the debate and to have opposite visions of the subject sitting at the same table and think that maybe both have rights; that not one has the truth and one has not – maybe both have the truth. You need to really conclude what is the best for the country and for the people of the country. That is … why I think it is so crucial that we debate these things openly.

In response to a question about the constituent elements of good government, R5 stated:

> To provide good regulation. To communicate well. To stimulate research. To debate on the subject and get the subject to the public before it is a reality.

Democracy, then, was viewed as both a moral value to be vindicated and a practical reality to be pursued.

"I think it is beneficial. But we have to be very responsible in this because Argentina has a trend to have discussions like a civil war, and some days it's not easy for the Argentinean society. But it is unavoidable. You have discuss things."

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[2] Although debates around stem cell research are often portrayed as a polarised conflict between several camps, most notably scientists versus religiously-motivated groups, this characterisation is rather simplistic. Reflecting empirical research in the UK (see A. Bruce & N. Marks, "Five Myths About Human Embryonic Stem Cell Research", Briefing No. 14, 2007, at http://www.genomicsnetwork.ac.uk/media/five%20myths%20about%20human%20embryonic%20stem%20cell%20research.pdf), not all researchers were non-religious, and not all those interviewed were convinced about the therapeutic prospects for (embryonic) stem cells (optimism was muted in part because of the perceived gap between experimental results and clinical reality. As such, despite their excitement, researchers were cautious about raising patient expectations. At least one researcher believed that the benefits of stem cell research may come from contributions to basic science, human disease modelling, bioreactor development, and pharmaceutical toxicity screening.

CONCLUSIONS AND RECOMMENDATIONS FOR ARGENTINA

We referred in the first paragraph to new social realities being characterised by socio-cultural convergence. While the GET: Social Values Project demonstrated several factors unique to the Argentine setting, it also supports the claim that recognition of international science and ethics standards and cross-jurisdictional value concepts is strong and widely shared. However, the extent to which 'international' (or not purely Argentinean) values play out on the ground is unknown, and deserving of further empirical ethnographic research.

Based on the evidence obtained in the GET: Social Values Project, we can make the following recommendations as it relates to the pursuit of bioscience in Argentina:

- Policymakers and practitioners should avoid hyperbole when discussing stem cell and regenerative medicine possibilities and futures.

- Policymakers, including Argentine research funding bodies as a constituent thereof, should encourage and fund further socio-legal research which investigates the Argentine social and science environments (and the interface between the two), including research on science funding practices, all with a view to generating an evidence base for further policy decisions as they relate to the biosciences.

- Policy-makers and practitioners should encourage and take the lead in undertaking broader consultations with a range of publics that consider (1) the value of science, (2) the values people hold in respect of science (or which are implicated by science), and (3) the appropriate boundaries for science (or alternatively, an appropriate means of setting boundaries on an ongoing basis for science).

- Policymakers should undertake concrete and sustainable collaborative efforts to enhance networks and foster a closer interdisciplinary science/policy/ethics community in the broad regenerative research and medicine field, including the use of regular interdisciplinary meetings. Such a network would encourage dialogue and idea-exchange, and would better prepare (and fortify) science protagonists to engage with broader publics.

- Policymakers and practitioners must be prepared to frame the context within which policy and public debates unfold (ie: write the lexicon, capture the imagination, and temper expectations, while engaging with concerns and desires expressed by the stakeholders and networks which choose or are invited to participate).

The above recommendations capture, at least in part, the facets of the democracy value implied in many of the respondents' interviews. Science democracy here embodies the idea of empowering the articulation by a broad range of stakeholders of science values and ambitions, and the consultation of a range of publics before decisions are made and policies are set.

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For more on the GET: Social Values project, visit
http://www.law.ed.ac.uk/ahrc/esrcvaluesproject/